

NEW YORK STATE RARE DISEASE WORKGROUP

AGENDA

March 8, 2023; 9-11am

- 1. Welcome and Introductions led by Workgroup Co-Chairs** *20 minutes*
Dr. Melissa Pittel Wasserstein
Chief, Division of Pediatric Genetic Medicine
Children's Hospital at Montefiore

Mary Wootten
Member Coordinator, The Oley Foundation
Volunteer New York Rare Action Network Ambassador, NORD

- 2. New York State Rare Disease Workgroup: NYS Legislation, Workgroup Charge and Workgroup Operations** *15 minutes*
Dr. Barbara Wallace,
Director, Division of Chronic Disease Prevention
New York State Department of Health

- 3. National Picture of States' Rare Disease Advisory Councils** *15 minutes*
Annis Reed
State Policy Manager, Eastern Region
National Organization for Rare Disorders (NORD)

- 4. Discussion of Workgroup Priorities, Subcommittee Development, and Recommendation Development** *30 minutes*
All members

- 5. Next Steps** *10 minutes*
Dr. Melissa Pittel Wasserstein, Co-Chair
Mary Wootten, Co-Chair